A Mission of Empowerment

By Jean Nash Johnson

A BRAIN TUMOR SHIFTS a psychologist's focus to helping survivors thrive

DAYNA SMITH

Michael Feuerstein turned his focus to cancer survivorship after being diagnosed with a brain tumor.

AFTER FIVE YEARS WITH BRAIN CANCER, Michael Feuerstein, 57, lives, sleeps and breathes for cancer survivorship. He is a survivor and he is a champion.

With advances in research and technology increasing the odds for beating cancer, greater emphasis on survivorship is needed in the medical community, says Feuerstein. Since his own 2002 diagnosis with a grade 3 anaplastic astrocytoma, the scientist for 29 years (with a PhD in clinical psychology) has made it his mission to help heighten the quality of life for those who have had cancer.

"He really feels he was saved for a reason," says his wife, Shelley, a school psychologist.

"Patients are living longer with cancer. I'm not an MD, but I am a scientist and I know a lot about this stuff, and *I* was scared," Feuerstein says from his office at the Uniformed Services University of Health Sciences in Bethesda, Md.

Feuerstein's goal is to buffer the fear factor for survivors by helping doctors communicate better with patients and by helping those who are healing to take command of their disease.

Fast Facts

NAME >>

Michael Feuerstein, PhD, MPH

OCCUPATION >>

Clinical psychologist and professor, Uniformed Services University of Health Sciences in Maryland

DIAGNOSIS >>

Brain tumor (grade 3 anaplastic astrocytoma in the right cerebellum)

AGE AT DIAGNOSIS >>

51

TREATMENT >>

Surgery to remove a small section of the tumor. Radiation and chemotherapy the first year. Currently gets regular MRIs.

CURRENT STATUS >>

Tumor has shrunk and is not visible on MRI. Work is harder for him now. It takes longer to digest what he's reading, yet he is able to work full days. He says he spends about 75 percent of his day, seven days a week, committed to his work on survivorship.

HOW CANCER HAS AFFECTED HIS LIFE >>

"While some survivors can just move on after primary treatment and don't have challenges or health problems, many of us do experience problems. These challenges come and go. It has been very helpful to me to see this cancer survivor thing as a journey with bumps in the road that when possible need to be repaired and maintained."

Michael and his wife, Shelley, with grandson Kiran COURTESY OF FEUERSTEIN FAMILY

SPREADING THE WORD

This year he launched the *Journal of Cancer Survivorship: Research and Practice,* published by Springer and aimed at healthcare professionals who need to understand lifestyle issues affecting patients from diagnosis into recovery. The quarterly journal, edited by Feuerstein, provides new information regarding the health, healthcare and quality of life for survivors. It includes research papers, case studies and articles from leading experts worldwide. A complementary publication, *Handbook of Cancer Survivorship,* provides a summary of important research in the area. (The journal is available at www.springer.com/journal/11764 or by calling [212] 460-1500.)

Feuerstein and coauthor Patricia Findley wrote *The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer* (Marlowe and Company, $15.95). It's filled with useful how-to's for coping after beating the odds.

His hard work and commitment is receiving notice. *Handbook of Cancer Survivorship* received a favorable nod in a June 14 review in *The New England Journal of Medicine.* Feuerstein and the *Cancer Survivor's Guide* were featured in an August *New York Times* story by health columnist Jane E. Brody about people thriving after cancer.

Who better to be advocate and authority? As a research scientist and academic, Feuerstein actively studies behavioral medicine and health psychology. His expertise on the patient side gives balance. However, unlike his careful planning for life as a scientist, there was no time to prepare for life with a fatal disease.

> **"Patients** ***are living longer with cancer. I'm not an MD, but I am a scientist and I know a lot about this stuff, and I was scared."*** —MICHAEL FEUERSTEIN

A LIFE-CHANGING MOMENT

In May 2002, a "perfectly healthy" Type A Feuerstein was heading to lunch near his office at Georgetown University Medical Center when he stepped off the curb to cross busy Wisconsin Avenue in Washington, D.C. "As I looked to the left and right, I wound up getting a little dizzy. As I tried to run across the street, I found that I couldn't really move my legs one in front of the other. It was a brief moment. After, I ran across wobbling, then hung on to a tree. The whole thing stabilized and I drove straight home."

Shelley's gentle voice bristles when she recalls him driving home not knowing what was wrong. "I don't know what he was thinking," she says. They have been married 35 years and have three children, Sara, 29; Andrew, 27; and Erica, 19. Their two grandkids, Sara's children, were born after the cancer. The brood has been Feuerstein's glue since the fateful street crossing.

That afternoon he saw his internist, who referred him to a neurologist. An MRI revealed a tumor growing in the right cerebellum. Days later he was in surgery at Baltimore's Johns Hopkins Hospital.

"I'll never forget the radiologist's words: 'I don't know what this is, but it looks pretty bad,' " Feuerstein says. He got his affairs in order, as he was advised, and began his battle. In spite of the prediction he would live only three months to a year, Feuerstein refused to die.

Shelley, 56, remembers the day of the procedure. She told neurosurgeon Howard Fine, MD, "Please be so careful because this is a very brilliant mind you're going into." She reassured the children, they comforted her, and the family waited.

Youngest daughter Erica, now a college sophomore, was 14. "What sticks out in my mind the most was when Dad called from the doctor's," she says.

"His voice sounded so scared, and when I asked what was wrong he firmly asked to talk to Mom. It was all so unreal. ... I kept most of my feelings inside. I would cry alone in my room so that my parents, especially my Mom, wouldn't see me upset."

It wasn't until Erica's senior year, when she wrote an essay about her Dad's experience, that Feuerstein understood the depth of Erica's grief. Her essay is printed in the survival guide under "Form a Support Team." In that chapter, Feuerstein emphasizes the vital importance of support.

FRIEND IN DEED

His own support came in the form of his colleague and friend Neil Grunberg, who now enjoys a close friendship with the family. Feuerstein had asked him to be available after surgery to explain the jargon to Shelley and the children.

Grunberg, a research scientist and professor specializing in animal model and behavioral medicine, works down the hall from

Feuerstein's university office and continues to lend support during the workday.

"It's important [for survivors] to have a supporter in the workplace — someone who will be honest and direct about how you're coming across, and help you be self-aware," Grunberg says. "After staff meetings, often Michael will ask, 'Was I too blunt?' "

Feuerstein appreciates Grunberg's feedback. "Many times it's not fair to burden family and friends. They get stressed, too." He advises survivors to talk to other survivors and join support groups.

As for his personal journey, it's what fuels his cause. His survival story shows that optimism and not giving up are vital components to thriving with cancer, he says.

AN IMPROVING OUTLOOK

After radiation and two months into chemotherapy, things started looking better. "Each MRI, the tumor kept shrinking. After a while you couldn't see it, which isn't necessarily good news. It's just not evident," Feuerstein says.

It wasn't bad news, either. So he keeps thrusting his agenda forward. He is consumed with changing the healthcare culture so that communication between provider and survivor improves.

Survivors should seek follow-up care without hesitation, he says. "Develop a healthcare team from diverse specialties and call on them when you need to. Don't ignore symptoms. They probably don't mean the tumor is back, but maybe you can get help for troublesome symptoms. Don't feel like you're being a hypochondriac, which is easy to do. "

Realistic optimism also is a good measure, he says. "This is not just being positive or hopeful all the time, but realizing you might have old and new health problems and new forms of stress from time to time."

Feuerstein realizes that his intensity about survivorship can seem overwhelming.

"My doctor says I'm like an alcoholic working in a bar. I do think about this too much," he muses.

It's important for him to stay on top of his crusade, says Shelley. "I'm getting used to it. We just try to keep a sense of humor," and when she can, she pulls him away from work to spend time with the grandchildren, who live nearby.

"The grandkids are a wonderful distraction," she says. **H**

Jean Nash Johnson is a feature writer based in Dallas.

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Feuerstein relies on fellow scientist Neil Grunberg for support at work.